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Washington State Health Care Authority Health Information Infrastructure Advisory Board (HIIAB)

Health Information Infrastructure Option:
Competitive Health Record Banking

Executive Summary

The HIIAB is considering several possible approaches to developing a health information infrastructure for the State of Washington that would provide immediate access to complete electronic patient information when and where needed. No specific plan for creating health information infrastructure has as yet been endorsed by the HIIAB. This document describes one proposed approach under consideration, known as "Competitive Health Record Banking." This draft document is being circulated both to the HIIAB members and various stakeholders for review and comment as part of the process that will ultimately lead to the development of final recommendations by the HIIAB later in 2006.

In "Competitive Health Banking," each person would designate an organization of their choice, known as a Health Record Bank, to be the holder of their complete lifetime health record (LHR). Each LHR "account" would contain copies of all the electronic health information available for that person, and be available to medical care providers (via a secure Internet portal) only with the explicit consent of the account holder or their designee. Whenever new medical information about the person was produced, it would be encrypted and sent electronically to a community clearinghouse where it would be forwarded to the Health Record Bank holding that person's LHR so that it could be added to the existing information. All producers of medical information would send copies of all new records to the community clearinghouse to ensure the completeness of each person's LHR (as required by HIPAA when requested by the account holder). Each Health Record Bank would, for those account holders who consent, perform searches of their non-identified LHR information for public health agencies and authorized medical researchers.

To financially support these activities, Health Record Banks would assess small fees to individuals for maintaining accounts, offset by charges for access to the information for research purposes. As needed, Health Record Banks may also pay fees for deposits of information into individual accounts. To protect the account holders, Health Record Banks would be required to meet established criteria for privacy and confidentiality, security, backup, and governance.

The community clearinghouse (which could serve the entire state), would be a non-profit organization governed by a balanced group of health care stakeholders (including strong representation from consumers). The clearinghouse would support its operations by charging small transaction fees to the Health Record Banks for information sent to them.

I. The Problem of Access to Health Information

In today's health care system, each person's medical records are usually scattered among multiple providers and institutions. While each such entity has records about the services they have delivered, no organization currently is responsible for collecting, maintaining, and providing for the immediate availability of a person's complete lifetime health record (LHR). Furthermore, most of the records are still paper, meaning that they are difficult to use even if available.

The absence of complete health information is clearly detrimental to the safety and quality of care, and results in substantial unnecessary costs from duplicative tests and procedures. The Institute of Medicine and others have documented serious problems from medical errors, which result in thousands of unnecessary deaths and other adverse outcomes each year. These errors are not due to poor performance by our hard-working, dedicated, and well-trained health care professionals, but rather are a result of a medical care system that does not consistently provide access to the complete and timely information they need for medical decisions.

II. The Role of Information Technology in Addressing the Problem

There is widespread agreement that converting the largely paper records used in the health care system into electronic form would save lives, improve the quality of care, and reduce health care costs by providing immediate access to complete electronic patient information when and where needed. There are at least two important components involved in achieving this goal. First, all the records must be electronic. This means that every doctor's office, hospital, long-term care facility, emergency room, etc., must use electronic medical records. However, even if all of a person's records are electronic, each such record is only a "slice" of the complete information. Therefore, the second component is a way to retrieve all the electronic information for a given person when it is needed for their medical care. This requires some type of communication mechanism among the various holders of electronic medical information. Together, these two components are known as "health information infrastructure."

Since the overwhelming majority of care received in a particular community is provided in that same community, health information infrastructure is being approached as a community project. Many communities have recognized the potential value of health information technology to solve the problem of delivering complete patient information when needed. While a few localities have made substantial progress toward this goal (e.g. Spokane and Bellingham, WA), no community has yet to establish a system that can provide complete electronic medical information. Therefore, there are currently no working models of such a system that can be adopted to solve this problem.

III. Key Criteria for Solutions

The key criteria developed by the HIIAB to evaluate potential solutions include:

- 1. each person's lifetime health record (LHR) should be immediately available when and where needed
- 2. privacy, confidentiality, and security of medical information must be protected
- 3. participation in the system should be voluntary and available to all
- 4. patients should be able to control who has access to any or all of their LHR and see a list of all accesses by others to their information

- 5. existing health information systems should be maximally leveraged to achieve the goals
- 6. the system should be financially sustainable
- 7. healthcare providers and institutions should be free to choose any electronic medical record system they wish as long as it communicates information using appropriate standards
- 8. with patient permission, the non-identified health information of the community should be available for public health and medical research

IV. Status of HIIAB Deliberations

The Health Information Infrastructure Advisory Board (HIIAB) is currently considering several possible approaches to creating health information infrastructure for Washington State. No specific approach has as yet been adopted, and the HIIAB is continuing to seek input from stakeholders before making a recommendation.

V. Competitive Health Banking (illustrated by accompanying animated slide)

A. Overview

The key premise of Competitive Health Banking is that each person's complete lifetime health record (LHR) should be in one place where it can be readily available for use when and where needed. Since the LHR is very sensitive and private information, each person should be able to choose the organization (known as a Health Record Bank) that holds it on their behalf. Furthermore, each person should totally control who has access to which parts of their LHR, including its possible use in non-identified form for medical research.

To implement such a system, Health Record Banks must be established. There must be a method for authorized users to access LHR information in the Health Record Banks. Also, there must be a system for ensuring that copies of new medical information are promptly deposited in each person's LHR so that it remains up-to-date and complete once established.

B. Health Record Banks

A Health Record Bank is envisioned as an organization that can provide to consumers an "account" for their LHR. It is anticipated that consumers will be charged a small fee for this service. In return, the Health Record Bank will collect and maintain the LHR, make it available in whole or in part to any health care professionals designated by the account holder, and offer the consumer the opportunity to make their non-identified LHR information available for medical research (in exchange for a portion of the fees charged by the Bank for such access).

A Health Record Bank would be responsible for receiving all new medical information for its account holders from the Community Clearinghouse (see next section) and promptly storing that information in the proper LHR. It would also implement policies and procedures to ensure the privacy and confidentiality of the LHR information, the physical and electronic security of the data, and secure backup to prevent data loss in the event of a disaster or other emergency. Finally, the Health Record Bank would be governed in an open and transparent manner so as to justify the trust of consumers.

One example of an organization that could readily offer Health Record Bank services is a large multi-specialty clinic that already has a sophisticated electronic medical record system for its own patients. Such an organization could provide LHRs for its own patients and even offer this service to other consumers who receive their care elsewhere. The Community Clearinghouse would ensure that any new medical information for account holders would be sent to the organization to add to the appropriate LHR.

To finance its operations, the Health Record Bank would assess small fees to individuals for maintaining accounts, offset by charges for access to the information for research purposes. As needed, Health Record Banks may also pay fees for deposits of information into individual accounts (for example, paying such fees to physicians for deposits of reports of outpatient encounters would provide strong incentives for acquisition and use of electronic medical record systems).

C. Community Clearinghouse

To ensure that the Health Record Banks are able to maintain complete LHRs for their account holders, new medical information must be sent to them as soon as it is produced. This is not an issue if the Health Record Bank for a given person is also the site where they receive all their medical care, but most people receive at least some care from non-affiliated organizations (e.g. outside laboratories). The Community Clearinghouse would be the organization that is responsible for receiving all new medical information generated in the community and forwarding it to the correct Health Record Bank for each individual.

To accomplish this task, the Clearinghouse would need to establish electronic connections with all the Health Record Banks as well as all the sources of electronic medical information in the community. It would also need to be able to identify the Health Record Bank for each item of medical information it receives (note: there are a number of ways this can be accomplished, but such details are outside the scope of the present document). Finally, the Clearinghouse would need to make agreements with Clearinghouses in other communities to be sure that information from community members receiving care in other areas is sent back properly.

To finance its operations, the Clearinghouse would charge small fees to the Health Record Banks for information delivered to them. To ensure neutrality with respect to the various Health Record Banks and other healthcare stakeholders, the Clearinghouse would be organized as a non-profit organization governed by a balanced group of health care stakeholders (including strong representation from consumers).

D. Advantages and Disadvantages

Advantages of the Competitive Health Record Banking concept include:

- 1. The Community Clearinghouse is simple to operate (and therefore inexpensive)
- 2. The Community Clearinghouse need not store any medical information whatsoever
- 3. A competitive market for Health Information Banks is created, which could result in lower prices and better service for consumers
- 4. Each person's LHR would be immediately available when needed from their Health Record Bank

- 5. Existing organizations with electronic medical record systems could easily offer Health Record Banking Services
- 6. The Community Clearinghouse could serve the entire state, resulting in economies of scale (and a single communication channel for receiving all out-of-state medical information)
- 7. Individual communities would be free to develop their local health information infrastructure in whatever way they choose as long as there is 1) access to LHRs for members of their community; and 2) an input channel where medical information generated outside the community could be sent. This includes adoption of either of the other two options under consideration, the scattered model (record locater service) or the single community Health Record Bank (see next section below).

<u>Disadvantages</u> of the Competitive Health Record Banking concept include:

- 1. a new community organization, the Community Clearinghouse, must be established (and funded)
- 2. Organizations must decide to offer Health Record Banking services
- 3. Choosing a Health Record Bank may be confusing for consumers
- 4. State-of-the-art physical and computer security methods must be used to protect the LHR information in each Health Record Bank
- 5. A mechanism must be established to assure that each Health Record Bank adheres to minimum consumer protections (to avoid the temptation to "cut corners" in a competitive market)
- 6. This approach does not necessarily provide incentives for physicians to acquire and use electronic medical record systems in their offices (Payments to physicians by Health Record Banks for submitting information could accomplish this, but are optional)

VI. Synopsis of Other Proposed Solutions

Full review of the alternative solutions is beyond the scope of this document. However, a brief synopsis of the other approaches is included to provide context.

A. Scattered Model (record locater service)

In this approach, there is no stored LHR. Instead, there is a community system (known as the "record locater service" or RLS) that keeps a record of where you've received care, but does not store any of the actual medical information. When needed, the system electronically requests your actual medical records from each place and puts them all together to create your LHR "on the fly." Whenever medical care is received, a message is sent to the RLS indicating that information is available from that source. Since all records in this model must be retrieved one-at-a-time, this approach does not accommodate use of the electronic medical information for public health and medical research.

B. Single Community Health Record Bank

This is a variation of the Competitive Health Banking approach with a single Health Record Bank storing the LHR for each person in the entire community. To do this, the community must establish the Health Record Bank (to ensure its neutrality). Since this single Health Record Bank receives all new medical information in the

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community, the Community Clearinghouse becomes unnecessary. As with the Community Clearinghouse, arrangements must be made with other communities to be sure that medical information for community members that is generated there is sent to the single Health Record Bank. With a single Health Record Bank in a community, incentive payments to physicians for standard electronic information would be more effective (in providing sufficient funds to pay for EHRs) because they would be paid for most patients seen in the community.

